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Health Status of Adolescent and Young Adult Cancer Survivors

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Abstract

BACKGROUND—Adolescents and young adults (AYA) ages 15 to 29 years who are diagnosed with cancer are at risk for long-term morbidity and mortality associated with treatment of their cancer and the cancer itself. In this article, the authors describe the self-reported health status of AYA cancer survivors.

METHODS—The authors examined 2009 data from the Behavioral Risk Factor Surveillance System, including demographic characteristics, risk behaviors, chronic conditions, health status, and health care access, among AYA cancer survivors compared with respondents who had no history of cancer.

RESULTS—The authors identified 4054 AYA cancer survivors and 345,592 respondents who had no history of cancer. AYA cancer survivors, compared with respondents who had no history of cancer, reported a significantly higher prevalence of current smoking (26% vs 18%); obesity (31% vs 27%); chronic conditions, including cardiovascular disease (14% vs 7%), hypertension (35% vs 29%), asthma (15% vs 8%), disability (36% vs 18%), and poor mental health (20% vs 10%) and physical health (24% vs 10%); and not receiving medical care because of cost (24% vs 15%).

CONCLUSIONS—AYA cancer survivors commonly reported adverse behavioral, medical, and health care access characteristics that may lead to poor long-term medical and psychosocial outcomes. Increased adherence to established follow-up guidelines may lead to improved health among AYA cancer survivors.*

Keywords

cancer; neoplasm; survivorship; adolescent cancer

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CONFLICT OF INTEREST DISCLOSURES

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INTRODUCTION

There have been improvements in cancer survival in the overall population of the United States over the last 30 years. However, adolescents and young adults (AYAs) have not experienced the same improvements as others with cancer.^{1–3} AYA cancer survivors—those ages 15 to 29 years at their first cancer diagnosis—have not experienced improvements in survival to the extent that younger children and older adults have.⁴ AYA cancer survivors also are at risk for long-term morbidity and mortality associated with treatment of their cancer and the cancer itself. Long-term survivors of cancers that were diagnosed during adolescence have an increased risk of death beyond 5 years compared with other cancer survivor populations.^{3,5,6} Among young adults, excess mortality is caused by cancer recurrence, subsequent neoplasms, and cardiovascular and lung disease as a result of treatment of the original cancer.^{3,7} Lifelong follow-up care is recommended for AYA cancer survivors, because this population is at risk for developing late effects related to their cancer treatments years later.^{3,5–10} However, providing follow-up care and tracking the long-term outcomes of AYA cancer survivors have been challenging. Most AYA cancer survivors are not followed in cancer survivorship programs and often are cared for by primary care physicians who may be unaware of the risks associated with AYA cancer and therapy.^{3,11}

Although the health status of other populations of cancer survivors has been well characterized, less is known about AYA cancer survivors.^{3,12,13} For the current study, we used the 2009 Behavioral Risk Factor Surveillance System (BRFSS) to describe demographic characteristics, risk behaviors, chronic conditions, health status, and health care access among AYA cancer survivors in the United States.

MATERIALS AND METHODS

The BRFSS is a state-based surveillance system that monitors health behaviors, chronic diseases, injuries, access to health care, and preventive health care on an ongoing basis. BRFSS methodology has been published elsewhere.^{14,15} The 2009 BRFSS survey included all 50 states, the District of Columbia, Puerto Rico, the US Virgin Islands, and Guam. The BRFSS is a cross-sectional, random-digit-dial telephone survey of noninstitutionalized adults aged 18 years that uses trained interviewers and standard core and optional questionnaire modules to collect uniform data across all states, Washington DC, and select US territories. Surveys are conducted with US households each month using disproportionate, stratified, random sampling in all states and Washington DC and simple random sampling in Guam, Puerto Rico, and the US Virgin Islands (available from: http://www.cdc.gov/brfss/technical_infodata/surveydata/2009.htm [Accessed January 23, 2012]). The median response rate according to the Council of American Survey Research Organization for the 2009 BRFSS was 52.5%.¹⁶

For 2009, the BRFSS included the cancer survivor module as a core module that was asked by all states, Washington DC, and territories. Respondents were asked whether they were ever told by a physician, nurse, or other health care professional that they had cancer. If respondents indicated “yes,” then they were asked how many different types of cancer they had, the age when they were told that they had cancer, and what type of cancer they had. Of

432,607 BRFSS respondents, 411,654 answered the “ever had cancer” question. Among these respondents, 45,541 reported ever having cancer (excluding nonmelanoma skin cancer; $n = 13,632$), and 348,229 reported never having any type of cancer. Respondents with an unknown history of cancer or who refused to answer the question were excluded from the analysis ($n = 4252$).

We conducted a descriptive analysis to obtain prevalence estimates with 95% confidence intervals for demographic characteristics, risk behaviors, chronic medical conditions, and preventive medical care among AYA cancer survivors and respondents who reported not having a history of cancer. We defined AYA cancer survivors as cancer survivors whose age at first cancer diagnosis was between ages 15 and 29 years. However, we only had data from survivors who were aged 18 years at the time of the interview, because the BRFSS only interviews individuals aged 18 years. Therefore, all patients who were diagnosed at age 15 years were at least 3 years out from their cancer diagnosis. We excluded AYA cancer survivors who did not report their current age ($n = 15$), which left 4054 AYA survivors in the final analysis. Respondents without a history of cancer and with a known age ($n = 345,592$) served as a comparison group.

For AYA cancer survivors, we calculated the number of years since diagnosis using the respondents’ current age and their age at first cancer diagnosis. We grouped years since diagnosis as 0 to 9 years, 10 to 19 years, and 20 years. Type of cancer was grouped as non-Hodgkin lymphoma, Hodgkin lymphoma, leukemia, melanoma, cervical cancer, other female reproductive cancer (ovarian, endometrial), male reproductive cancer (prostate, testicular), thyroid, brain, female breast, colorectal cancer, other, and unknown/refused.

We examined the following demographic characteristics: age at interview, sex, racial/ethnic background, marital status, education level, employment status, and US Census region of residence. In addition, we analyzed current smoking status, binge drinking (males who had 5 and females who had 4 alcoholic drinks on 1 occasion in the past month), obesity (body mass index ≥ 30 kg/m²), no leisure-time physical activity in the past month, and <5 servings of fruits and vegetables per day. We analyzed the following chronic health conditions: cardiovascular disease (history of myocardial infarction, angina, coronary disease, or stroke), hypertension, diabetes, current asthma, and disability (activity limitations because of physical, mental, and emotional problems). Physically and mentally unhealthy days were categorized as 0 to 13 days and 14 days during the past 30 days. The following health care access variables also were examined: health insurance coverage, inability to visit a physician because of cost in the past 12 months, access to a personal health care provider, and a routine checkup in the past 2 years.

Final survey weights were included that represented each respondent’s probability of being selected for the survey in their respective state or territory and were adjusted to race/ethnicity-specific, age-specific, and sex-specific population numbers from current census data (or intercensal estimates). All estimates were weighted to represent noninstitutionalized adults aged 18 years living within their respective state, Washington DC, Puerto Rico, US Virgin Islands, or Guam. We used the SAS statistical software package (version 9.2; SAS Institute Inc., Cary, NC) and SAS-callable SUDAAN (release 10; Research Triangle

Institute, Research Triangle Park, NC) to account for the complex sampling design of the BRFSS. Because AYA cancer survivors tended to be largely female and younger compared with respondents who had no history of cancer, all prevalence estimates with the exception of those for years since diagnosis, age at interview, type of cancer, and sex were age-standardized and sex-standardized to the total BRFSS population. We used nonoverlapping 95% confidence intervals as a measure of significance.

RESULTS

We identified 4054 AYA cancer survivors and 345,592 respondents who had no history of cancer (Table 1). AYA cancer survivors had a significantly younger median age at interview (40 years) compared with respondents who had no history of cancer (43 years). The most common identified type of cancer among AYA cancer survivors was cervical cancer (38%), followed by other female reproductive cancer (13%), and melanoma (9%). Significantly lower proportions of AYA cancer survivors were non-Hispanic blacks and Hispanics (6% and 8%, respectively) compared with respondents who had no history of cancer (10% and 15%, respectively). A significantly greater proportion of AYA cancer survivors reported being out of work/unable to work (24%) compared with respondents who had no history of cancer (14%).

Table 2 lists risk behaviors, chronic medical conditions, self-reported healthy days, and health care access. Current smoking was significantly greater among AYA cancer survivors (26%) compared with respondents who had no history of cancer (18%). There was no difference in binge drinking between AYA cancer survivors and respondents who had no history of cancer (14% vs 15%). More AYA cancer survivors also reported no leisure-time physical activity in the past month compared with respondents who had no history of cancer (31% vs 24%). Compared with respondents who had no history of cancer, AYA cancer survivors had a greater prevalence of cardiovascular disease (14% vs 7%), hypertension (35% vs 29%), disability (36% vs 18%), asthma (15% vs 8%), and diabetes (12% vs 9%). Compared with respondents who had no history of cancer, a greater proportion of AYA cancer survivors reported 14 days of poor mental health in the past 30 days (20% vs 10%) or poor physical health (24% vs 10%) in the past 30 days. There was no statistical difference in health insurance, personal health care providers, or a physician checkup in the past 2 years between the 2 groups. However, a significantly greater proportion of AYA cancer survivors reported not being able to visit a physician because of cost (24% vs 15%). Because of the large number of self-reported cervical cancer survivors, we also performed our analysis excluding cervical cancer survivors. After removing cervical cancer survivors from the overall group of cancer survivors, only 2 estimates were statistically significantly changed: sex and individuals reporting “other” for employment status.

DISCUSSION

In this report, we describe the health status of AYA cancer survivors in the United States using BRFSS data. Our findings reveal that AYA cancer survivors commonly reported unhealthy behaviors, chronic medical conditions, poor health-related quality of life, and

significant barriers to health care access, which may lead to poor long-term medical and psychosocial outcomes.

Our results are consistent with previous literature describing adverse health conditions, including smoking, chronic medical problems, functional limitations, and poor self-reported health status, among various cancer survivor populations.^{17–22} Evidence suggests that modifiable risk behaviors among cancer survivors, including smoking, alcohol use, and obesity, may be associated with cancer recurrences and the development of second primary cancers.²³ Cancer survivors, including adolescent cancer survivors, who continue to smoke are at increased risk for second malignancies and chronic conditions.^{24,25} Despite this risk, 26% of AYA cancer survivors reported current smoking. This was significantly higher than the proportion of respondents who had no history of cancer and it also was higher than previous reports of current smoking among childhood, adolescent, and adult cancer survivors.^{26–30} This highlights an important public health problem that may benefit from effective cessation interventions, such as peer-delivered smoking counseling.³¹ Although effective tobacco treatment programs exist, research suggests that health care providers miss opportunities to provide smoking-cessation advice and treatment.³² Our results suggest that AYA cancer survivors should be a priority for interventions to prevent the initiation of smoking and for smoking-cessation interventions.³³ This is especially true for adolescents, because their intention to smoke is closely correlated to future smoking.³³ Limiting alcohol use also has been suggested for cancer survivors given the potential mutagenic effects of alcohol that may place cancer survivors at risk for second cancers or increased late effects.^{30,34,35} Despite these risks, there was a similar proportion of binge drinking among AYA cancer survivors compared with respondents who had no history of cancer. This indicates a need for interventions to decrease the initiation and consumption of alcohol among AYA cancer survivors. We also observed that a significantly greater proportion of AYA cancer survivors were obese and reported no leisure-time physical activity in the past month compared with respondents who had no history of cancer. Although research suggests that vigorous physical activity increases survival among survivors of breast and colorectal cancer,^{36–38} exercise training is likely to be beneficial for most cancer survivors.^{39,40} The American College of Sports Medicine has indicated that exercise training sufficiently improves physical functioning and quality of life for cancer survivors.⁴⁰ The lack of physical activity among cancer survivors may be because of physical limitations as a result of cancer treatment and the cancer itself. Therefore, the availability of individualized physical fitness programs, such as Live-Strong at the YMCA, may be of benefit to cancer survivors.⁴¹

A significantly greater proportion of AYA cancer survivors reported having cardiovascular disease, hypertension, asthma, and diabetes compared with respondents who had no history of cancer. This is consistent with late effects of cancer treatment, including cardiac and pulmonary complications, among childhood cancer survivors.^{34,42} The increased incidence of medical conditions, such as diabetes, may be from the increased rate of obesity in cancer survivors compared with the general population and may not be caused solely by late effects of cancer therapy.^{36,43,44} Long-term follow-up guidelines published by the Institute of Medicine and the Children's Oncology Group (COG) recommend lifelong follow-up care for childhood, adolescent, and young adult cancer survivors based on cancer history and treatment.^{45,46} COG recommendations provide guidance on potential late effects, risk

factors, screening and evaluation, counseling, and other interventions.⁴⁶ Compared with young adults, children with cancer are more likely to be treated in COG-associated institutions. Health care providers at these COG institutions may be more likely to be aware of and adhere to the COG long-term follow-up guidelines compared with other hospitals. Therefore, young adults may receive care from health care providers who are not as familiar with guidelines recommending appropriate follow-up for AYA cancer survivors. Efforts to improve providers' knowledge and use of recommended guidelines, such as the American Society of Clinical Oncology and LiveStrong's Focus Under Forty program,⁴⁷ are needed to address the numerous health needs of AYA cancer survivors. Improving the quality of care for AYA cancer survivors also may include the use of survivorship care plans, which were recommended by the Institute of Medicine in 2006.^{48,49} Survivorship care plans are designed to improve the quality of care for cancer survivors through summarizing cancer treatments, describing potential late effects of treatment and cancer, recommending appropriate screening, and promoting healthy behaviors.^{49,50}

We observed that a greater proportion of AYA cancer survivors reported disability compared with respondents who had no history of cancer. This may be because of the late effects of cancer treatment as opposed to aging, because AYA cancer survivors as a group were younger than respondents who had no history of cancer at the time of interview, and our results were age-adjusted. A greater proportion of AYA cancer survivors also reported more poor mental and physical health in the past 30 days compared with respondents who had no history of cancer. Our results, although they were based on different methodology and populations, are consistent with previous literature indicating that adolescents who are diagnosed with cancer report low health-related quality of life.⁵¹ Disability also has been associated with poor health-related quality of life and risk behaviors, including smoking, lack of physical activity, and obesity.¹⁸ Our results indicate that this combination of disability and risk factors may be particularly problematic for AYA cancer survivors.

Although we observed no differences between the AYA population and respondents and noncancer controls in terms of health insurance status, a significantly greater proportion of AYA cancer survivors could not visit a physician because of cost. This may be because of financial strain caused by the high cost of cancer treatment, which results in an inability to pay for copayments, medications, transportation, and other services.^{52,53} This is consistent with studies indicating that, compared with individuals who have no history of cancer, cancer survivors are more likely both to delay and to forgo medical services because of cost.⁵³ The inability to visit a physician because of cost also potentially may be related to a lower overall level of income in cancer survivors. Lower income in this population potentially may be a long-term result of derailment of patients' education/employment trajectories during their cancer treatment and may be unrelated to any lingering effects of the cost of cancer therapy.

Our study has several limitations. BRFSS data are self-reported and may be subject to recall or social desirability bias. For cancer in particular, survivors are likely to over-report and under-report, depending on the cancer type.^{54,55} Cervical cancer survivors were the largest self-reported group in our study, which differs from estimates reported from cancer registry data.⁵⁶ This discrepancy may be caused by over-reporting. There is evidence that

respondents of health interview surveys over-report certain types of cancer, including cervical cancer.⁵⁵ Women who are diagnosed with cervical intraepithelial neoplasia or other squamous cell abnormalities may mistakenly believe that they have cervical cancer. However, women typically are diagnosed with cervical cancer, which is highly treatable if detected early, at younger ages relative to other cancers, and this may contribute to a large cervical cancer survivor population.⁵⁷ There was no medical record review to confirm self-reported cancer type and other responses. BRFSS is administered through landline telephones. Therefore, there may be bias present because of the exclusion of individuals who do not have a landline telephone.⁵⁸ BRFSS also is limited to noninstitutionalized individuals and may not be representative of the general population. BRFSS is not administered to individuals aged <18 years of age. Therefore, AYA cancer survivors younger than age 18 years were not included in this study.

AYA cancer survivors are at risk for late effects from treatment, cancer recurrences, and second malignancies as a result of their cancer and its treatment. Although guidelines for long-term follow-up aim to prevent and minimize poor outcomes, increasing adherence to these guidelines and implementing evidence-based interventions to promote healthy behaviors and reduce adverse risk behaviors are needed to improve the health of AYA cancer survivors.

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Table 1

Demographic Characteristics of Survivors of Adolescent and Young Adult Cancers and Respondents Without a History of Cancer: Behavioral Risk Factor Surveillance System, 2009

Characteristic	Percentage (95% CI) ^a	
	Survivors of Adolescent and Young Adult Cancer Diagnosed at Ages 15 to 29 Years ^b	Respondents Without a History of Cancer ^b
Total no.: Unweighted	4054	345,592
Total no.: Weighted	1,934,779	194,913,730
Time since diagnosis, y		
0–9	28.5 (25.5–31.8)	—
10–19	26.7 (24–29.6)	—
20	44.8 (41.9–47.7)	—
Median age at interview, y	40.2 (38.7–41.4)	42.9 (42.8–43.1)
Type of cancer		
Non-Hodgkin lymphoma	2.4 (1.2–4.7)	—
Hodgkin lymphoma	5.3 (4–7)	—
Leukemia	1.5 (0.9–2.4)	—
Melanoma	8.5 (7.2–10)	—
Cervical	37.7 (34.8–40.6)	—
Other female reproductive	13.1 (11.1–15.4)	—
Male reproductive	2.9 (2.1–4.1)	—
Thyroid	3.7 (2.9–4.9)	—
Brain	1 (0.6–1.8)	—
Female breast	4.8 (3.9–5.9)	—
Colorectal	1.5 (1–2.3)	—
Other	14.5 (12.5–16.9)	—
Unknown/refused	3 (2.1–4.3)	—
Sex		
Male	18.9 (16.4–21.7)	49.2 (48.8–49.6)
Female	81.1 (78.3–83.6)	50.8 (50.4–51.2)
Race/ethnicity		
White, non-Hispanic	78.5 (75–81.6)	67.5 (67.2–67.9)
Black, non-Hispanic	6.1 (4.7–7.9)	10.3 (10.1–10.5)
Native Hawaiian/Asian/Pacific Islander, non-Hispanic	— ^c	3.6 (3.4–3.8)
AI/AN, non-Hispanic	1.4 (1–1.9)	1 (1–1.1)
Hispanic	7.9 (5.8–10.6)	14.7 (14.4–15)
Multiracial	3.8 (2.2–6.4)	1.5 (1.4– 1.6)
Education		
<High school	10.3 (8.6–12.3)	10.6 (10.4–10.9)
High school graduate	27.5 (24–31.2)	28.1 (27.8–28.4)
Some college	29.3 (25.6–33.3)	26.6 (26.3–26.9)

Characteristic	Percentage (95% CI) ^a	
	Survivors of Adolescent and Young Adult Cancer Diagnosed at Ages 15 to 29 Years ^b	Respondents Without a History of Cancer ^b
College graduate	32.9 (29.7–36.3)	34.6 (34.3–34.9)
Employment		
Employed for wages	49.4 (45.4–53.5)	57.5 (57.2–57.8)
Out of work/unable to work	23.5 (19.9–27.5)	13.7 (13.5–14)
Other	10.6 (8.5–13.3)	12.8 (12.6–13.1)
Retired	16.2 (14.3–18.3)	15.7 (15.5–15.8)
US Census region of residence		
Northeast	16.1 (13.6–19)	18.1 (17.9–18.3)
Midwest	22.6 (19.2–26.4)	22.1 (21.9–22.3)
South	39.1 (35.4–43)	36.5 (36.2–36.8)
West	21.9 (19.1–24.9)	21.9 (21.7–22.1)

Abbreviations: AI/AN, American Indian/Alaska Native; CI, confidence interval.

^a Cancer survivors with nonmelanoma skin cancer were excluded. All estimates other than age, sex, years since diagnosis, number of cancers, and cancer type are age and sex standardized.

^b Ninety-five percent CI percentages may not total 100% because of rounding. Unknown/refused categories are suppressed for most variables; therefore, percentages may not add to 100%. Data for territories are suppressed.

^c Data suppressed, number of respondents < 30.

Table 2

Risk Behaviors, Chronic Conditions, Self-Reported Health Status, and Health Care Access Among Survivors of Adolescent and Young Adult Cancers and Respondents Without a History of Cancer: Behavioral Risk Factor Surveillance System, 2009

Characteristic	Percentage (95% CI)	
	Survivors of Adolescent and Young Adult Cancer Diagnosed at Ages 15 to 29 Years ^a	Respondents Without a History of Cancer ^a
Risk behaviors		
Current smoker	25.9 (23–28.9)	17.9 (17.6–18.1)
Binge drinker	13.8 (11.1–17)	15.1 (14.8–15.3)
Obese: BMI ≥ 30 kg/m ²	30.8 (27.2–34.7)	26.7 (26.4–27)
No leisure-time physical activity in past mo	30.5 (27.2–33.9)	24.3 (24–24.6)
<5 Servings of fruits/vegetables	78.7 (76.1–81.2)	76.3 (76–76.6)
Chronic conditions		
Cardiovascular disease	14.2 (11.7–17.2)	7.4 (7.3–7.5)
Hypertension	35.1 (31.6–38.7)	29.1 (28.9–29.4)
Disability	36.3 (32.4–40.3)	18.1 (17.9–18.3)
Current asthma	15.2 (12.7–18.1)	8.3 (8.1–8.4)
Diabetes	11.8 (10–14)	9 (8.9–9.2)
Poor mental health in past 30 d		
0–13 d	79.7 (76.6–82.5)	88.6 (88.4–88.9)
14 d	19.5 (16.7–22.6)	10.2 (10–10.4)
Poor physical health in past 30 d		
0–13 d	73.7 (69.4–77.5)	88.4 (88.2–88.6)
14 d	23.9 (20.3–28.1)	10.1 (9.9–10.3)
Health care access		
No health insurance access	15 (12.2–18.4)	15.2 (14.9–15.5)
Could not see a physician because of cost	23.9 (20.5–27.6)	14.7 (14.4–15)
Had personal health care provider	86.2 (83.4–88.6)	80.8 (80.5–81.1)
Saw a physician for checkup in past 2 y	82.4 (79.5–84.9)	81.3 (81–81.6)

Abbreviations: CI, confidence interval; BMI, body mass index.

^aCancer survivors with nonmelanoma skin cancer were excluded. All estimates are age and sex adjusted to the Behavioral Risk Factor Surveillance System, population.